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Journal of Central Nervous System Disease

DOI:

[10.1177/1179573519843872](https://doi.org/10.1177/1179573519843872)

Published: 13/05/2019

Publisher's PDF, also known as Version of record

[Cyswllt i'r cyhoeddiad / Link to publication](#)

Dyfyniad o'r fersiwn a gyhoeddwyd / Citation for published version (APA):

Hughes, S., Woods, R., Algar-Skaife, K., Jelley, H., & Jones, C. (2019). A Collaborative approach: Care staff and families working together to safeguard the quality of life of residents living with advanced dementia. *Journal of Central Nervous System Disease*, 11, 1-9.
<https://doi.org/10.1177/1179573519843872>

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A Collaborative Approach: Care Staff and Families Working Together to Safeguard the Quality of Life of Residents Living With Advanced Dementia

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Journal of Central Nervous System Disease
Volume 11: 1–9
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DOI: 10.1177/1179573519843872



ABSTRACT

OBJECTIVES: This study aimed to explore the quality of life and well-being of care home residents living with advanced dementia, how personalised care can be achieved where the person is completely dependent on others for care and how individuals' choices and human rights were upheld.

METHODS: The study design used a qualitative approach, with data collected through in-depth, semi-structured interviews with 8 family members, all of whom visited daily, and 8 care staff.

RESULTS: Emerging themes highlighted the importance of family involvement, signs of well-being, communication and the valued role of direct care staff.

DISCUSSION: Participants were able to identify factors of residents' well-being in residents living with advanced dementia. Family members who visited daily saw themselves working collaboratively with care staff to maintain the quality of life of their relatives and engage in proxy decision making. Regarding human rights, the emphasis was on avoiding abuse, rather than promoting well-being.

KEYWORDS: advanced dementia, well-being, quality of life, human rights

RECEIVED: May 4, 2018. **ACCEPTED:** March 21, 2019.

TYPE: Original Research

FUNDING: The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: Sian Hughes' PhD studies are funded by a Knowledge Economy Skills Scholarship (KESS 2) from Bangor University in partnership with Fairways Care and the Drapers' Company. The KESS 2 programme is funded by the European Social Fund.

DECLARATION OF CONFLICTING INTERESTS: The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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Introduction

In 2014, an estimated 311,730 persons with dementia were resident in care homes in the UK, making up seventy percent of all care home residents.¹ Given the increased prevalence of the condition with age and an ageing population with longer life expectancy, the number of people affected by dementia continues to grow. Care home placement is often required as individuals progress into the later stages; as the average age of people with dementia becomes older, there is an increased risk of care home placement being required due to the greater likelihood of physical health comorbidities and of outliving potential care partners.^{2–4}

In recent years, a focus on the quality of life (QoL) has become increasingly prevalent within the study of dementia.^{5–8} There is also increasing attention on well-being and rights of people living with mild to moderate dementia, yet, despite this, we understand much less about how to identify and support well-being and human rights in people with advanced dementia.⁹ It is crucial not to overlook the needs of those at their most vulnerable in the later stages of dementia, particularly where individuals are completely dependent on others and may be unable to verbally communicate their wishes.

Individuals living with advanced dementia are at increased risk of having their rights overlooked. Kelly¹⁰ found a lack of

support for individuals living with advanced dementia in care homes in contrast to other terminal illnesses.¹¹ The right to dignity, autonomy and protection from abuse is universal, regardless of the cognitive or physical decline.^{10,12} Reduced cognitive function threatens the right to autonomy, so that people living with dementia are reliant on surrogate decision making, whereby family members and care staff become their decision makers. This process may lead to their human rights not being continuously considered.¹³ This may not necessarily be a deliberate act, as situations may occur where an organisation's practices and procedures disadvantage a certain group of people; this is known as 'indirect discrimination'.¹⁴ For example, people living with dementia may be excluded from making decisions regarding their care planning. Regardless of the intentions, the effects are severe and have been termed as 'social death'.¹⁵ A self-advocacy organisation for people living with dementia has suggested that there is a negative perception of human rights, coupled with a lack of understanding.¹⁶

Moving into a care home setting leads to changes in a person's social and physical environment, which may result in changes to their QoL. Care homes are able to provide various facilities and professional care for individuals living with dementia, high-quality care provision and person-centred care.¹⁷ Despite this, research comparing QoL of individuals



living with dementia in the community with those living in care settings reports that living in the community is associated with higher QoL.^{17,18} Factors contributing to QoL, eg, higher levels of independence and social inclusion, differ for individuals living in the community compared with those residing in care home settings.^{18,19} Living in the community allows individuals to maintain a role in family life, a place in the community and social connections. Contributors of QoL may be different in the later stages of dementia, where factors in the early stages, such as independence, may be less significant, when safety and comfort may take primary importance.²⁰ Therefore, it is necessary to understand the factors affecting QoL, to support and maintain QoL²¹ for those individuals who progress into the later stages who require care home placement, and who receive increasingly intensive care.⁵ Alzheimer's Disease International²² states that research is well established with other chronic diseases, but the quality of life has not been widely included in investigations of advanced dementia.

Alzheimer's Disease International²² categorises different stages of dementia by different levels of impairment and health care needs. Research suggests care homes are having difficulty supporting residents with advanced dementia.²³ This is due to little advanced care planning and lack of knowledge of residents' distressing symptoms, which becomes increasingly challenging for care providers.^{12,23} Identifying care preferences combined with increased care planning and specialised training could contribute to better care provision, for residents living with advanced dementia.¹²

Aim

This study aimed to explore the quality of life and well-being of care home residents living with advanced dementia, and to explore how personalised care can be achieved when the person is completely dependent on others for care and may no longer be able to verbally communicate their wishes. We also explored how individuals' choices and rights were upheld and how staff or relatives dealt with decisions made in the best interest of a person with advanced dementia. This study provides an opportunity to consider human rights in dementia with the aim of identifying what supports a positive cultural shift, from risk of abuse of human rights to promotion. This article focuses on qualitative interviews conducted with family members and care home staff supporting people living with advanced dementia.

Methods

Design

The research took place across 2 specialised dementia care home facilities, operated by an independent care home group (Fairways Care) in North Wales. The 2 care homes comprise of individual households for people living with dementia. One care home has 3 households, with the capacity for up to 32 residents, and the other home has 4 households with the capacity

of up to 48 residents. The research arose from a partnership with Fairways Care as part of the Knowledge Economy Skills Scholarship (KESS 2) programme. The KESS 2 is a major European Convergence programme led by Bangor University on behalf of the Welsh higher education sector, offering collaborative research projects (Research Masters and PhD) associated with a local company partner.

Measures

An initial assessment to assess the severity of dementia of the residents living with dementia involved using the Clinical Dementia Rating (CDR) scale.²⁴ The CDR assessment was rated by the researcher from information provided by care staff. The CDR was introduced by the researcher as part of the research project. Staff were able to indicate possible residents who would meet the criteria. The CDR scale is widely used and measures stages and severity of dementia with 0 indicating no impairment and stages 0.5, 1, 2 and 3 indicating questionable dementia, mild, moderate and severe dementia, respectively. The scale includes 6 domains: memory, orientation, judgement and problem solving, community affairs, home and hobbies and personal care.²⁴ Care staff also completed the Functional Assessment Staging (FAST)²⁵ on each individual in the study. The FAST procedure encompasses the progression of Alzheimer disease in 7 stages. The FAST stages begin at (stage 1) normal to (stage 7) severe dementia. Residents meeting the criteria for advanced dementia in this study were expected to meet criteria 6 or 7.

Ethical Issues

Following ethical approval from the North Wales Research Ethics Committee (17/WA/0015), February 17, 2017, eligible participants were approached by care home managers and the researcher. Information leaflets and posters were available throughout the home. The potential participants were given information sheets along with consent forms in Welsh or English depending on preference detailing the aims and procedures of the study. Following discussion of the project with the researcher, written consent was sought from relatives and staff members prior to interviews. All participants provided consent to take part in the interview, including consent for audio recording of the interviews.

Participants

Family members of residents living with advanced dementia (CDR 2-3; FAST 6-7) were identified by the care home managers and senior care staff. Relatives of a resident were invited to participate if they had regular contact with their relative in the home, to ensure good knowledge of the individual's lived experiences. Several participants expressed an interest in taking part independently. Where possible the researcher recruited a relative of the resident and a staff member to provide information about the same resident during the separate qualitative interviews. In each case, the researcher made participants aware

that their involvement was voluntary, and if they chose not to participate, this decision was fully respected by the researcher. Care staff members had to have good knowledge of the resident and their daily lived experiences. All residents who were eligible to partake were approached to take part in the wider research project. From 80 possible residents living at the homes, 13 were identified as eligible and 10 were involved in the project.

Participant Characteristics

Data were collected from 16 participants comprised 8 relatives and 8 staff members. Data collected from relatives included 7 spouses (4 women, 3 men) and 1 woman adult child aged 57 to 81 (mean = 72) years. All were white European origin, and all spouses had retired, with 1 adult child in clerical occupation. Participating relatives had contact with the individual living with dementia, at least 4 days a week. The staff participants comprised 5 care assistants, 1 care practitioner, 1 nurse and 1 activities coordinator, 7 women, and 1 man aged 21 to 66 (mean = 43) years. Participating staff members worked full-time hours and were in contact with the resident, a minimum of 3 days weekly. Two relatives, who had intended to participate, did not do so, due to the death of their relatives between recruitment and the research commencing. One relative declined, as she struggled to come to terms with her husband's condition as well as care home placement. Three care staff members declined to take part, anxious regarding giving incorrect answers, possible repercussions of talking about their employment and not having enough time. The sample size was determined by the residents who met the criteria for advanced dementia and the willingness of their relatives/key staff members to participate.

Semi-Structured Interviews

The researcher conducting the interviews was a familiar face within the homes, attended resident family meetings and undertook induction shifts at both homes. The researcher continued to see participants at the home after their scheduled interviews as it was part of a wider project thesis. Therefore, the researcher had the opportunity to build a rapport with participants before, during and after interviews. Interviews conducted lasted between 20 and 80 minutes, and the interviewer advised participants that they could ask any questions during the interview and that there were no correct or incorrect answers. If participants were unsure, the interviewer would explain further and participants were encouraged to talk about the subject area as they wished. To assist participants respond to the human rights questions, the researcher provided participants with a copy of the DEEP 'Our Dementia, Our Rights' guide, written for and with individuals living with dementia, setting out simply the key domains: equality, inclusion, privacy and security, dignity and the right to life.

A topic guide (Table 1) was developed through consultation with the project research team and advisory group of individuals

Table 1. Semi-structured interview topic guide for relatives and staff members.

INTERVIEW QUESTIONS
<p>How is well-being expressed in the individuals?</p> <p>How is quality of life and well-being monitored?</p> <p>If you are making a decision on the individual's behalf, what is the reason for this?</p> <p>How do you know when you are making a decision on this person's behalf that it is in the best interest of the individual?</p> <p>What is the assumption you make about the individual's ability to make decisions about their daily lives?</p> <p>What are your views and experiences on human rights in advanced dementia care?</p> <ul style="list-style-type: none"> • How are they maintained and promoted <p>Does living in a care home make a difference to living in the community, in terms of human rights?</p>

living with dementia. Semi-structured interviews with participants were on a one-to-one basis with the researcher in the care homes. During interviews, participants were able to express their thoughts and feelings on other related topics.

Data Analysis

Interviews were transcribed from digital recordings and all personal identifiers removed to retain anonymity and participants were each assigned a pseudonym and participant number. The researcher listened back to digital recordings after transcribing to ensure accuracy of the coding. The qualitative research software programme NVivo was used to support coding and analysis of the data to enhance rigour.²⁶

An inductive thematic analysis approach (bottom up) was adopted,²⁷ and a framework was used for identifying and coding words and phrases of importance. The researcher identified some themes that were linked to the topic guide during the coding phase of the analysis. Therefore, an inductive and deductive approach took place during the course of data analysis.

The potential themes were identified before further analysis using the NVivo software to support coding of the data and identifying emerging themes. During this procedure, the researcher placed extracts of the interview transcripts into nodes identifying initial themes. The themes were reviewed to ensure the extracts fitted the given theme, and no further relevant extracts were within the data set.²⁷ The researcher coded the data independently and met regularly with the research team to discuss the coding process, themes and subthemes. The themes and subthemes were refined and modified with the research team to ensure trustworthiness, and a final consensus was reached.

Participant Validation

Following the data analysis procedure, participants were invited to discuss the project results and provide feedback. This provided meaningful feedback from participants to assist the researcher in developing the interview topics for further research and validation of the participants.²⁸ Preliminary findings were presented at the care homes, where participants and others were able to give their views and ask for further information, if

Table 2. Themes and subthemes.

THEME	SUBTHEME
Well-being	Physical signs of well-being. Who he or she used to be.
The girls	Staff and relative relations. Family involvement.
Communication	Importance of communication between staff, residents and relatives
Human rights	Decision making

required. During discussion attendees confirmed that the findings of the research did resonate with their experiences and therefore no further changes or analysis was considered necessary. The researcher ensured that the findings were written in accessible language as highlighted by Langdridge.²⁹

Results

The themes (see Table 2) incorporate views of the relatives and care staff relating to individual residents. Although the themes identified were the same, sometimes the staff and relatives offered a different perspective.

Well-being

Relatives and staff members identified factors that they associated with the well-being of the individual residents. Within this theme, 2 subthemes have been identified. The first of these related to *physical* signs of well-being such as food and fluid intake and body language, which were described as indicators of the person doing well. Some staff and relatives related eating well with the resident's well-being. Relatives discussed how a number of residents who would refuse to eat and drink at home had improved since being at the care home receiving support from the care staff:

We were seeing the dietician three days a week and they (dieticians) came on Saturday and said can't believe the weight he's put on he wouldn't even eat at home for you. But he's put that three stone back on in the year (since care home admission). (P7, Wife)

The care staff commented how they were able to see the physical signs of the residents' well-being through body language, as well as verbally:

He does chuckle and he does smile. His eyes do light up when there's . . . I mean he does sort of chat as well, and say things, and join in. So you know, that's the way I think he expresses his well-being really. He does laugh and things. He can express. You can see that yeah. (P9, Activities Coordinator)

However, one staff member commented,

He doesn't show us any emotions, he is expressionless. (P12, Care Assistant)

Care staff explained how working on one household allowed them to recognise individual residents' typical behaviours:

If he's really not happy about something he'll have that really angry look on his face. With brow furrows and everything, and other times he's, you know, he'll throw his rubix cube and smiles, you know, so you can tell, he's got that cheeky twinkle in his eye. (P16, Care Assistant)

The second subtheme of well-being was, 'who he or she used to be'; this related to moments where participants could see the individual irrespective of their dementia.

Relatives and staff members referred to residents' interactions as a sign of their well-being. Relatives shared the enjoyment of these moments:

She'll come out with all four of them (children's names), so you get these moments it's what you come for really. You know, those little moments and she comes out with vintage Shirley, you know. (P8, Husband)

Sharing these moments with the residents is comforting for families, and staff members are able to connect with who the residents used to be, as well as the here and now:

You know her old character, who she used to be. It is nice to see her in good spirits, you know, displaying ways she used to be. The way she was at home in a way, you know, mischievous. (P8, Daughter)

The girls

The care staff members were referred to by the participants as 'The girls', a term of endearment used by families, regardless of the number of male workers at the care homes. Within this theme, 2 subthemes were identified: *staff and relative relations* and *relative involvement*. The first of these referred to the rapport between the care staff members and the relatives:

Relatives commented how the care staff knew their personal preferences and adhered to them:

And the girls will try and coordinate things and match them because they know that's how I am and that's how she used to be. So you know little things like that. (P2, Husband)

Some relatives commented on how the care staff carry out their roles that it was more than a job to them.

They do it naturally here these girls, don't they. They put their arms round them you know. (P1, Husband)

Staff members valued their relationship with the families on the households:

There's a lovely rapport between the family members on (household) and the staff and you know more like a family really. (P9, Activities Coordinator)

The care staff not only supported the residents in the care home but the family as a whole.

We have a laugh with the staff as well and you might not be able to do that elsewhere and it helps. You know little things like that makes it lighter for us as well. (P8, Daughter)

The relationship the care staff have established with the relatives encouraged *relative involvement*:

We come to help them at lunch times. Because they've got so many that need feeding. If I can give Maureen, then that will save them then doing Maureen. When I'm not here then okay fine. (P2, Husband)

Care staff and relatives commented that their relationship allowed the households to be individual homes with individual communities:

It's easier isn't it when you've got family members here, who have got their, you know, knowledge of, you know, the person. And what their interests and likes or dislikes or . . . any, you know, that's first-hand knowledge isn't it really. (P9, Activities Coordinator)

Human rights

Participants discussed how *human rights* were maintained and promoted within the care home settings:

Well they would be the same really at home with me wouldn't they? But then I would be getting him out every day. (P7, Wife)

One participant commented on the discussion surrounding human rights at the care home:

I don't think anybody ever talks about human rights, no need probably. (P1, Husband)

A number of relatives discussed how their residents' human rights have improved, since being at the care home.

I feel that she has more rights here I think, because if she was living at home she wouldn't have that care would she. (P8, Daughter)

Relatives discussed the importance of the continuity of care, which is what their relatives received within the home.

They do change staff but the majority of them are on this floor all the time. So it's not that again strangers keep coming in and going out all the time you know. (P2, Husband)

However, some participants did consider that human rights must change following moving to the care home. They referred to care homes as institutions, and although it may not be a deliberate act, institutionalisation can take over the identity of the individual:

They have to change, at home I was in full command. I see certain things, but it can't be done, because there's not enough staff on. I came in today and he had this Rugby shirt on, it's very easy just shoving an old T shirt on but I don't like that. He was always a

gentleman and that's my James, and I want him to be seen as a gentleman. (P3, Wife)

Because the care home staff were attempting to meet the needs of a number of residents at the same time, the same relative noted that there were occasions when meeting the needs of one resident impinged on the rights of others:

Three is not enough (referring to the number of care staff on a household) there is very disruptive residents here, then two of them have to assist. Leaving one in the lounge and they've got a number of residents here, who can be very disruptive and having one person to deal with that is not enough. Not good enough, it's not giving the rest of the residents enough attention. (P3, Wife)

In relation to *decision making*, where decisions had to be made on behalf of the resident, relatives made decisions based on their knowledge of that person, personal preferences, past experiences and arrangements they had made prior to care home placement.

You have to make decisions on their behalf and you do it hand on heart. And you hope that that is what they would want you to do. (P7, Husband)

The care staff explained that they would discuss any decisions with the relatives.

I mean we wouldn't do anything that we would know (husband) wouldn't be happy with, again working together with everyone. (P10, Care Assistant)

Communication

Within this theme, one subtheme focused on the *importance of communication* between residents, care staff, care home managers and families.

The staff commented on letting residents know what is happening and providing them with reassurances:

Communication is key. It's key in dementia care. Letting them know what's happening and you know talking through things. (P9, Activities Coordinator)

Families discussed residents' preferences and routines with the care staff:

I work well with these guys so if I'm not here what I'm doing is asking them to get her up before 11 because she hates personal care. (P1, Husband)

Care staff monitored the resident's well-being and communicated with the rest of the team and relatives about the individual.

I would speak to everyone else and the nurses and the relatives, and check back with the documents and stuff. (P18, Care Practitioner)

Relatives and care staff discussed how they communicated well with each other about the resident's daily care.

There's a disconnect between the care staff and the nursing staff. Has she had her medication? Oh I don't know, I'll go and ask the nurse. (P1, Husband)

In relation to *communication*, the care staff and relatives recognised the resident's perception of events may be different:

But it's amazing how they use their body language to tell us that there's something not right. (P12, Care Assistant)

Relatives and care staff recognised the resident's different perception may lead to unexpected responses.

So if she doesn't like you, It doesn't mean she doesn't like you because the next minute she wants to kiss you. (P7, Husband)

The care staff appreciated the different ways residents interact with them, recognising that what they say may not necessarily be what they are trying to communicate:

There's other days where he would just say yes. And you wouldn't know whether he meant yes or no. But yeah that's what you think but that isn't probably what they are thinking. (P13, Care Assistant)

Discussion

Summary of findings

This study aimed to explore the quality of life and well-being of people living with advanced dementia in care home settings. This included an exploration when the person had limited or reduced capacity of the safeguards that were in place to ensure their rights and choices were at the forefront of care.

Well-being

The relatives and care staff members discussed factors they associated with the residents' well-being and QoL. Indicators of residents' well-being were derived from 'physical' indicators: food and fluid intake, mood, interactions and facial expressions such as smiling, laughing, eye gaze, verbal and nonverbal behaviours. Furthermore, families placed an emphasis on moments of clarity and identity 'who he or she used to be' as markers of well-being. The previous research findings suggest higher ratings of QoL are associated with responsiveness,⁹ social contact and activity.^{30,31} A case study set in a care home with a lady, 'Jessie', living with advanced dementia indicated that although Jessie had difficulty producing meaningful conversation, she maintained the urge to communicate and participate in social interactions and activity.³¹ Jessie's most frequent behaviours in response to interaction were smiling, laughing and eye gaze, termed as 'happy behaviour'. This is in line with the factors found in this study, highlighting the need for social activity to be maintained for the residents' well-being.

Further benefits for residents' well-being involved the physical environment.³² Although a number of residents were not able to engage fully in a particular activity, they were able to experience passive enjoyment of the environment. Lawton³³ placed emphasis on the effect of environment in contributing to an individual's quality of life. The person-environment system is crucial to QoL for a person with advanced dementia in a care home.⁶

A number of residents had gained weight since moving to the care homes and relatives considered this to be a factor reflecting well-being. Sharing mealtimes provides social cues from others, which increases appetite, food consumption and pleasure.^{34,35} A good daily intake of food and fluid, and weight gain are often used as markers of well-being.³⁵

Relatives in particular place emphasis on occasions where the resident showed signs of their individual character and personality, as it was prior to the onset of the dementia. Such moments provide families and care staff with a shared experience with the resident, which is an additional benefit, a type of reminiscence.³⁶ Furthermore, relatives understandably compare the past with the present, reinforcing the notion that 'they are still there'. For the care staff, who did not have any previous connection to the residents before their illness, these moments allow staff to appreciate the residents' characters' lives. This enabled the care staff to develop a deeper understanding of certain behaviours initially perceived as problem behaviours arising from the dementia, but which may equally be understood in terms of the person's life story and lifestyle.³⁷ Understandably, the dementia journey can cause family members a sense of loss and grief for the loved one they once were.³⁶ Despite this, participants found these moments of clarity as a comfort and indicators of their relatives' happiness in the home.

'The girls'. The care staff were known in the homes as 'the girls', a term of endearment. The well-being of the residents was maintained by the girls, who were seen as providing excellent care intuitively, as reported by the relatives. Families were heavily reliant on 'the girls' for their support, expertise and monitoring of their relatives' QoL as well as contributing to their own well-being. For families, care home placement comes where it is not possible for the individual to continue living at home. However, in this study, the caregiving role had changed rather than ceased for the relatives. Families in this study felt enabled by 'the girls' in their new caring roles. As families continued to provide care for their relatives, they became an advocate sharing their knowledge of the individual's preferences. These findings support the triangle of care notion,³⁸ which states that involvement of families equips care staff with better whole person knowledge and insights into how dementia can affect their behaviour and overall QoL.

Family involvement is one of the most significant contributors to residents' well-being.³⁹ The previous research by Gaugler⁴⁰ identified care homes where staff members recognised family

needs as well as the individual living with dementia were most likely to achieve good relations with family members.

Communication. Communication between the care staff and family members is fundamental for knowledge, decision making and coordinating caregiving efforts. Despite this, families expressed a concern for the lack of communication between the nurses and the care assistants. Frustration arises from this breakdown, as the nurses held the information regarding residents' medications but were not permanently on the households.

Care staff and family members took into account the resident may interpret things differently. For example, a resident's distress during personal care may be a result of feeling exposed, vulnerable and a lack of understanding about what is happening to them.⁴¹ They recognised different communication narratives, such as shouting and calling out, as a sign of discomfort and not being able to express how residents were feeling in any other form. Furthermore, families and care staff discussed the different forms of social dialogue they had with the residents. They used different methods, using body language and gestures and tone of voice to communicate. They recognised that the dialogue may not much make sense linguistically but enabled the resident to remain in the social world, allowing residents to contribute to the conversation.³¹

Human rights. Human rights were not widely discussed within the care homes, coupled with confusion and negative perception surrounding human rights in care homes.

As reported in the "Results" section, one participant commented, 'I don't think anybody ever talks about human rights, no need probably'. A guide to the rights of people living with dementia written by people living with dementia¹⁶ suggests that people view human rights from a negative perspective, avoiding human rights violations rather than promoting them positively. Accordingly, residents' rights were considered to be maintained by the lack of signs of physical abuse, whereas bruising and scratching may be visible on care staff members. It is widely recognised that people living with dementia may fall victim to physical abuse as a result of, what may be perceived as, challenging behaviour within care homes.^{11,42,43} A negative perception of human rights prevents open discussion, and the current dialogue placed an emphasis on violation of rights rather than promotion. However, 7 family members felt that their relative's human rights within the care home were maintained. This is supported by the literature stating care homes provide an environment that involves a high standard of care, safety,^{44,45} dignity,^{45,46,47} continuity of care staff members and person-centred practice.^{46,48} Furthermore, families commented on the staff recognition of the residents as individuals. In line with personhood theory by Kitwood,⁴⁹ recognising individuals living with dementia as people and supporting their personhood promote their well-being. As residents with advanced dementia in care homes are at their most vulnerable, it becomes

the responsibility of the care provider to sustain and promote care practices, which enables the individual's personhood.

In contrast, there is evidence in the literature focusing on human rights of people living with dementia, experiencing a lack of dignity and rights within care homes.^{10,11,42,50} Despite this, the continuity within the team reassured families that decisions were taken with the resident's best interest and not decided upon by strangers. Importantly for the care team, their justification for making decisions on behalf of the residents stems from the resident's inability to make choices in support of their QoL and well-being and ensuring best interests.³⁸

In terms of care home practice, it would be beneficial to have more open discussion regarding the promotion of human rights. Removing the current stigma would allow residents, families and staff to discuss openly, and reflect on what their human rights mean to them.

Strengths and Limitations

The exploratory nature of the research project results in a relatively small sample, with 2 participating care homes, both from the same care home group, incorporating a common ethos and similar day-to-day practices and a number of senior staff members working across both homes. However, this allowed the researcher to dedicate considerable time within the homes, interviewing and observing participants, and becoming familiar with residents, families and care staff. The interviews provided relatives with the opportunity to share their experiences and gave care staff a chance to tell their story, allowing for richness of data to be gathered. Family members who volunteered to take part in the study were heavily involved in their family member's care, and the outcomes may not transfer to relatives who may not have the opportunity to maintain, yet change, caring roles as their relative moved to a care home. The researcher became embedded within the homes; as a part of the project, the researcher had undertaken a full staff induction at both homes and was able to observe the daily running of the care homes as well as the interactions, relationships and daily challenges. During this time, the researcher could observe the importance of the themes in practice.

One limitation that should be acknowledged is participation bias; as is common with all research, staff with higher job motivation were more likely to partake in this study. Also, given the high demand of workload within care homes, this could limit the amount of time the staff felt that they could provide to partake in the study. A further limitation relates to the relative lack of detailed, in-depth discussion of human rights; although we attempted to support participants in considering these through providing a copy of the easy-to-read DEEP guide beforehand, it appears further support may have been needed. In future studies, having interview questions explicitly addressing key aspects, such as respect, equality, dignity and autonomy, rather than a general question, may be more productive.

Conclusions

This study adds to the evidence base on the quality of life and well-being of people living with advanced dementia. The study provides evidence of signs of well-being of people living with advanced dementia in care home settings. In addition, the research highlights views of family members who maintain a high level of involvement, once their family member moved into a care home. Moreover, the study demonstrates the benefits of the triangle of care, the advantages of having a positive relationship between care staff and families and the impact this has on the resident. Based on these findings, to deliver person-centred care in advanced dementia, we recommend tailoring care towards individuals' needs and preferences, as opposed to expecting individuals to fit in with the routines and practices of the service. This requires close collaboration and a good relationship with family members and adequate staffing so that individual preferences can be respected. Whilst our study has highlighted the importance of family involvement in care homes, not all residents will have families that are involved in their care. This presents a challenge for those supporting people living with advanced dementia in care homes. The settings in this particular project (households) referred to as 'individual communities' enabled family members to form relationships with each other and with residents on the households. Consequently, individuals who did not have their own family member were often involved, at least passively, with visitors being mindful of such residents. Staff should be aware that these residents will rely even more on them for social interaction and activity and that they may be at increased risk of becoming socially isolated. The British Geriatrics Society (BGS)⁵¹ state that care home staff become both advocates and facilitators, and should be equipped with the skills for that role. However, numerous professionals are now linked with the role of advocacy, leading to an unclear view of what it entails exactly and who is best suited to this position.⁵² Despite numerous views of who is nominated for this role, Schwartz⁵² states the relationship the care-worker has with residents is one of care, where best interests of the individual are at the core of care practices and decisions. If this were the case, then arguably the individual should not need anyone else to ensure this on their behalf, but regularly reported lapses in the care system suggest this may not be sufficient in all instances.

The study highlights that human rights are not widely discussed within the homes and information regarding them is not readily available. The study identifies a gap in the current knowledge and some confusion of what human rights are and their application in care homes. The lack of knowledge regarding human rights within advanced dementia needs to be addressed to support a change in the current culture and include the aspirations of people affected by dementia.¹⁶ As a way forward towards integrating human rights-based practice in advanced dementia care with person-centred care, we

recommend small but effective steps, returning to basic principles. Families and staff need to ask questions such as 'What's important to the individual here? Have they been given the opportunity to make their own choice as best as they can? If I'm making a decision on their behalf, is it within their best interests?' Rights can then be understood at a human level, rather than through lengthy documents, ensuring individual needs are met, rather than simply avoiding harm.



Acknowledgements

The authors would like to thank the participating care homes, care staff and families for their time and contributions.

Author Contributions

This work was undertaken as part of SEH's PhD programme. The study was originally conceived by KA-S, HJ and BW. SEH undertook all interviews and observations. All authors were involved in the analysis and interpretation of the data and participated in drafting and revising the manuscript. Final approval was obtained from each author prior to journal submission.

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